Topic 16: *Caregiving/Mistreatment of Older Adults*

Competencies

1. Define caregiving and describe demographics related to caregiving of older adults.
2. Identify specific positive and adverse consequences associated with caregiving.
3. Discuss resources available to caregivers of older adults.
4. Describe the role of grandparents as caregivers.
5. Describe the types and indicators of and contributing factors to elder mistreatment.
6. Discuss strategies for the reporting, treatment, and prevention of elder mistreatment.

Topic 16: *Caregiving/Mistreatment of Older Adults*

Content Outline

1. **Define caregiving and describe demographics related to caregiving of older adults.**
   - Caregiving is defined as unpaid assistance rendered to an older person by family or friends. Families provide 80% of the caregiving in the United States.
   - Over 80% of disabled older adults are residing in the community.
   - At least 3 out of 4 older persons rely solely on families and friends for support/assistance.
   - Between 2 and 3 million persons are involved in a caregiver relationship with an older adult.
   - Caregivers are predominantly women (72%).
   - Many spouse caregivers are as frail as their spouses.
   - Approximately 25% of employed persons in the United States are providing care to cognitively or physically disabled older adult family members.

2. **Identify specific positive and adverse consequences associated with caregiving.**

   A. Positive consequences associated with caregiving:
      - Satisfaction in caregiver role.
      - Increased self-esteem.
      - Fulfillment of family obligations/roles.

   B. Adverse consequences associated with caregiving:
      - Depression/anger/anxiety.
      - Fatigue/hypertension/back pain.
      - Increased psychoactive medication use.

- Caregivers may be at higher risk for substance abuse, domestic violence, noncompliance with medical advice, and abuse or neglect of their impaired relative.
- Women must often leave the workforce as a result of caregiving activities.

3. Discuss resources available to caregivers. (See Resource Section in this chapter for agencies.)
- Adult day care.
- Respite programs.
- Caregiver support groups.
- Community mental health services.
- Organizational resources by type of disease or illness (Stroke, Parkinson's Association, Alzheimer's Association).

4. Describe the role of grandparents as caregivers.

A. Demographics
- 5% (over 3 million) children live with their grandparent(s):
  12% Black
  6% Hispanic
  4% Caucasian
- Parenting is also done by great-grandparents.
- Age of grandparents parenting children:
  50%—45–55 years
  35%—55–75 years
  15%—Over 75 years

B. Stresses of grandparent caregiving:
- Inadequate assistance from other sources.
- Dangerous neighborhoods.
- Drug abuse by parent or child.
- Parenting again—especially having a sense of failure with their first parenting experience.
- Grandparent's life on hold.
- Inadequate knowledge of the legal system regarding guardianship.
- Inadequate respite care for these elderly grandparents.
- Inadequate finances to purchase what children need or want.

5. Describe the types and indicators of and contributing factors to elder mistreatment.*

A. *Elder mistreatment* is a general term for both abuse and neglect.

B. Prevalence:
- Between 1.5 and 2 million older adults reported mistreatment annually.
- Often unreported. Estimated only 1 in 14 cases reported.
- Expected increase in number of cases of elder mistreatment.
- Family violence is now a public health issue.

Reprinted by permission. American Medical Association, *Diagnostic & Treatment Guidelines on Elder Abuse*, 1992.

Content Outline

C. Types of elder mistreatment

Physical Abuse: Acts of violence that may result in pain, injury, impairment, or disease. Examples include:

- Pushing, striking, slapping, pinching, cutting, burning.
- Force-feeding.
- Incorrect positioning.
- Improper use of physical restraints or medications.
- Sexual coercion or assault (sexual contact or exposure without the older person's consent or when the older person is incapable of giving consent).

Physical Neglect: Failure of the caregiver to provide the goods or services that are necessary for optimal functioning or to avoid harm. This may include:

- Withholding of health maintenance care, including adequate meals or hydration, physical therapy, hygiene, medicines.
- Failure to provide physical aids such as eyeglasses, hearing aids, or dentures.
- Failure to provide safety precautions.

Psychological Abuse: Conduct that causes mental anguish in an older person. This includes:

- Verbal berating, taunting, harassment, or intimidation.
- Threats of punishment or deprivation.
- Treating the older person like an infant.
- Isolating the older person from family, friends, or activities.

Psychological Neglect: Failure to provide a dependent elderly individual with social stimulation. This may involve:

- Leaving the older person alone for long periods of time.
- Ignoring the older person or giving him or her the "silent treatment."
- Failing to provide companionship, changes in routine, news, or information.

Financial/Material Abuse: Misuse of the elderly person's income or resources for the financial or personal gain of a caretaker or advisor, such as:

- Denying the older person a home.
- Stealing money or possessions.
- Coercing the older person into signing contracts, signing over assets or assigning durable power of attorney to someone, purchasing goods, or making changes in a will.

Financial/Material Neglect: Failure to use available funds and resources necessary to sustain or restore the health and well-being of the older adult.

Violation of Personal Rights: Ignoring the older person's rights and capability to make decisions for himself or herself. This failure to respect the older person's dignity and autonomy may include:

- Denying the older person his or her rights to privacy.

- Denying the older person the right to make decisions regarding health care or other personal issues, such as marriage or divorce.
- Forcible eviction and/or placement in a nursing home.

Self-Abuse or Self-Neglect: Any of the activities above committed by the elderly person by himself or herself.

D. Indicators of elderly mistreatment

Physical Mistreatment
- Unexplained injuries.
- When the explanation is not consistent with the medical findings.
- When contradictory and/or inconsistent explanations are given by the patient and the caregiver.
- Signs of physical abuse include bruises, welts, lacerations, fractures, burns, rope marks, (note bilateral injuries and injuries in various stages of healing); laboratory findings indicating medication overdose or undermedication; and unexplained venereal disease or genital infections.
- Signs of physical neglect include: Presence of dehydration, malnutrition, pressure ulcers, poor personal hygiene, lack of compliance with medical regimens.

Psychological Mistreatment
- Excessive weight gain or loss.
- Insomnia or excessive sleeping.
- Withdrawn, depressed, or agitated.

- Signs of infantile behavior.
- Expressions of ambivalent feelings toward caregivers or family members.

Financial Mistreatment

- If the elderly person suffers from substandard care in the home despite adequate financial resources.
- If the elderly person seems confused about or unaware of his or her financial situation, or has suddenly transferred assets to a family member.

E. Contributing factors to elder mistreatment:
- Elder mistreatment occurs among men and women of all racial, ethnic, and socioeconomic groups.
- The perpetrator of abuse or neglect is often the spouse or an adult child of the older person, but paid or informal caregivers may also be involved.
- Most neglect is due to ignorance, lack of resources, or the frailty of the elder caregiver.
- Physical, functional, or cognitive problems or inordinate stress in caregivers.
- Mental illness, alcoholism, or drug abuse in the older person or caregiver.
- Social isolation, dependence, and physical illness of the elderly person.
- A past history of abusive relationships.
- Financial or other family problems.
- Inadequate housing or unsafe conditions in the home.
- Victims often experience several forms of elder mistreatment at the same time.

Topic 16: *Caregiving/Mistreatment of Older Adults*

Content Outline

6. Discuss strategies for the reporting, treatment, and prevention of elder mistreatment.

A. Reporting

Nearly all states require designated health-care professionals to report suspected elder mistreatment to a state authority (e.g., The Adult Protective Service Agency, Department of Aging). Most states have a 24 hour toll-free number for reports of abuse and neglect. Calls are confidential.

The professional has to raise the question—has to ask about mistreatment.

B. Treatment (See Instruments/Scales section)

- *Elder Abuse Assessment Form* (T. Fulmer; 1992).
- Screening & Assessment of Elder Mistreatment (*Diagnostic Treatment Guidelines on Elder Abuse & Neglect;* 1992).
- Interventions for Elder Mistreatment (*Diagnostic & Treatment Guidelines on Elder Abuse & Neglect;* 1992).

C. Prevention

- State adult protective or ombudsman programs.
- Interdisciplinary team approach.
- Community support groups focusing on aging parents, home care, domestic violence, financial and legal planning.
- Teaching self-care, care for the caretaker, stress reduction and relaxation techniques.
- Respite care.

Topic 16: *Caregiving/Mistreatment of Older Adults*

Instruments/Scales

A. *Elder Abuse Assessment Form*, see p. 16-11.

B. Screening & Assessment of Elder Mistreatment (*Diagnostic & Treatment Guidelines on Elder Abuse & Neglect;* 1992).

C. Interventions for Elder Mistreatment (*Diagnostic & Treatment Guidelines on Elder Abuse & Neglect;* 1992).

Instruments/Scales

ELDER ABUSE ASSESSMENT FORM

Date:_____ Person completing form:_____

Patient Information:

Name:_____ Age:_____ Unit #:_____

Address:_____
Street City, State, Zip Telephone #

Residence: Home ☐ Nursing Home: ☐ W10 form attached: ☐ Yes ☐ No

Accompanied to ER by:

Name

Street Address City, State, Zip

Phone #_____ Relationship to Patient_____

Family Contact Person:

Name

Street Address City, State, Zip Phone #

Reason for visit: (Please check primary reason)

Cardiac ☐ Orthopedic ☐ Fall ☐ GI ☐ Psychiatric ☐

Changed mental status ☐ Other (describe)_____

Current mental status:

Oriented ☐ Confused ☐ Unresponsive ☐

Who provides home care? _____

(Continued)

Source: Fulmer, T., & Walker, M. (1992). Elder Mistreatment Assessment as a Part of Everyday Practice. *Journal of Gerontological Nursing, 18*(3), 42–45. Used by permission.

Instruments/Scales

ELDER ABUSE ASSESSMENT FORM (Continued)

1. General Assessment	GOOD	BAD	UNCERTAIN	CAN'T GET INFORMATION
a. Clothing				
b. Hygiene				
c. Nutrition				
d. Skin integrity				

Additional Comments: _____

_____

_____

_____

_____

2. Possible Abuse Indicators	YES	NO	UNCERTAIN	CAN'T GET INFORMATION
a. bruising				
b. lacerations				
c. fractures				
d. various stages of healing of any bruises or fractures				
e. evidence of sexual abuse				
f. statement by elder re: abuse				

(Continued)

Instruments/Scales

ELDER ABUSE ASSESSMENT FORM (Continued)

3. Possible Neglect Indicators	YES	NO	UNCERTAIN	CAN'T GET INFORMATION
a. contractures				
b. decubiti				
c. dehydration				
d. diarrhea				
e. depression				
f. impaction				
g. malnutrition				
h. urine burns				
i. poor hygiene				
j. repetitive falls				
k. failure to respond to warning of obvious disease				
l. inappropriate medications (under/over)				
m. repetitive hospital admissions due to probable failure of health care surveillance				
n. statement by elder re: neglect				

4. Possible Exploitation Indicators	YES	NO	UNCERTAIN	CAN'T GET INFORMATION
a. misuse of money				
b. evidence				
c. reports of demands for goods in exchange for services				
d. inability to account for money/property				
e. statement by elder re: exploitation				

(Continued)

ELDER ABUSE ASSESSMENT FORM (Continued)

5. Possible Abandonment Indicators	YES	NO	UNCERTAIN	CAN'T GET INFORMATION
a. evidence that a caretaker has withdrawn care precipitously without alternate arrangements				
b. evidence that elder is left alone in an unsafe environment for extended periods of time without adequate support				
c. statement by elder re: abandonment				

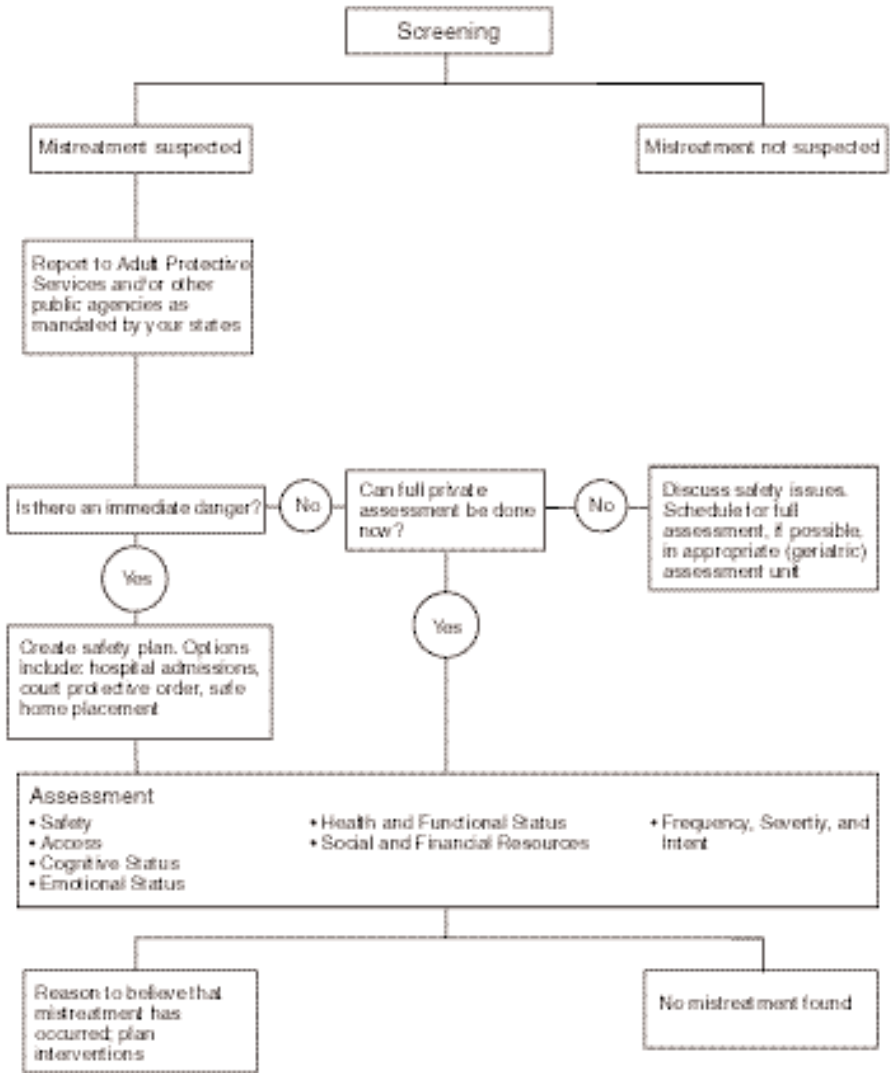
Summary	YES	NO	UNCERTAIN	CAN'T GET INFORMATION
a. evidence of abuse				
b. evidence of neglect				
c. evidence of exploitation				
d. evidence of abandonment				

Comments:

Instruments/Scales

Intervention and Case Managment: Part 1

Screening and assessment for elder mistreatment shold follow a routing pattern. Assessment of each case should include the following:

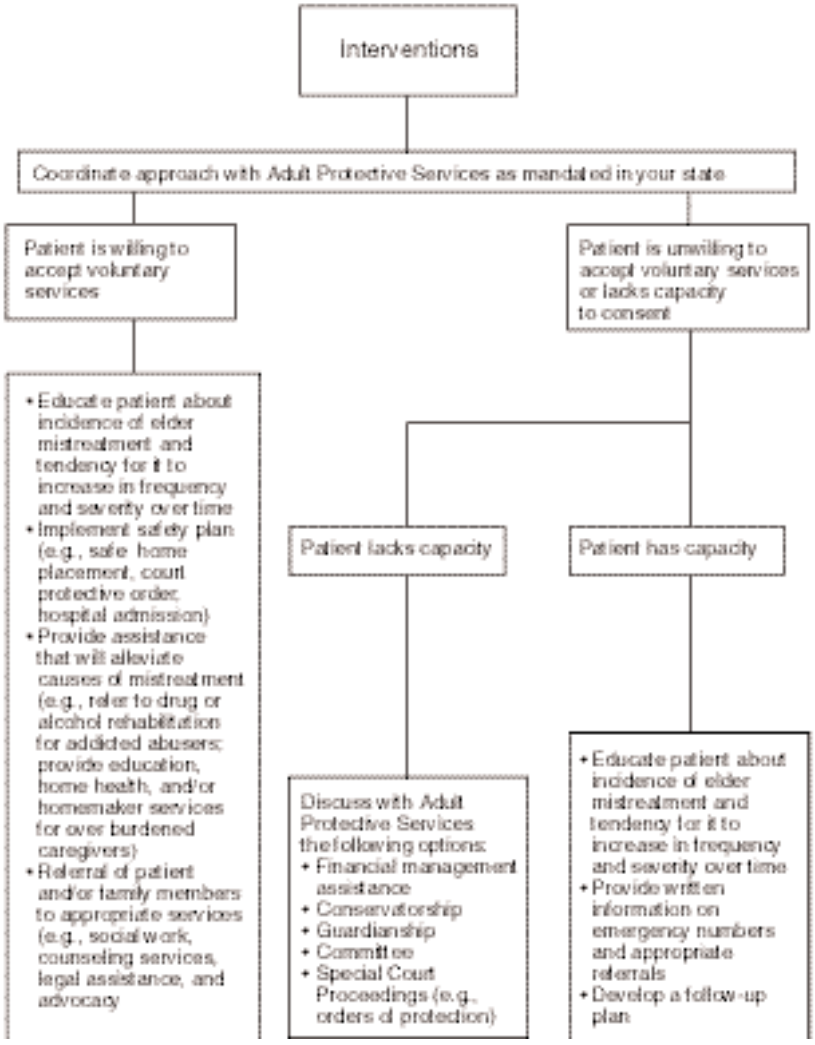


Reprinted with permission of the American Medical Association, *Diagnostic and Treatment Guidelines on Elder Abuse and Neglect* 1992: 13.

Instruments/Scales

Intervention and Case Managment: Part 2

Case management should be guided by choosing the alternatives that least restrict the patient's independence and decision-making responsibilities and fulfill state mandated reporting requirements. Intervention will depend on the patient cognitive status and decision-making capability and on whether the mistreatment is intentional or unintentional.



Reprinted with permission of the American Medical Association, *Diagnostic and Treatment Guidelines on Elder Abuse and Neglect* 1992: 13.

Topic 16: *Caregiving/Mistreatment of Older Adults*

Case Study

Ms. R is an 85-year-old woman who lives in a New York City apartment with her 60-year-old daughter, Ms. S. Ms. R was born in Puerto Rico and moved to the mainland United States shortly after she was married, and all of her four children were born in New York. Three of Ms. R's children are married, and two of them, along with their spouses, retired and moved to the Miami area a few years ago. One daughter lives in central New Jersey. Ms. R has 11 grandchildren, and five of them live within an hour of New York City. Ms. S has never married, and after her mother was widowed, Ms. S gave up her own apartment and moved in with her mother.

Ms. R was diagnosed with diabetes in her fifties, and also has arthritis. About five years ago, Ms. R became increasingly forgetful, and her family attributed this to her advancing age. Over time, however, her forgetfulness worsened, and for the past year or so Ms. R has been unable to prepare meals or dress herself appropriately. Accordingly, Ms. S would dress her mother and prepare all her meals, all while working full-time in a nearby office.

Recently, Ms. R developed a high fever and was diagnosed with pneumonia. Her physician admitted her to the hospital, where her daughter sits at her bedside for most of the day. When you speak to Ms. S., she tells you that Ms. R frequently seems to "lose track of time." In fact, before admission to the hospital, Ms. R was awake much of the night at home and slept during the day. As a result, Ms. S says she herself is very tired most of the time and is experiencing difficulty at work.

After a few days of intravenous therapy and antibiotics, Ms. R recovers from her pneumonia, and plans are made for her to be discharged home. Ms. S expresses concern to you that her caregiving responsibilities are becoming somewhat overwhelming, and she is feeling very stressed.

Topic 16: *Caregiving/Mistreatment of Older Adults*

Experimental/ Clinical Experiences

A. **Define/Discuss:** Discuss the reciprocal nature of family relationships over the life span, including a description of the affect of functional and/or cognitive decline of any family member. Discuss how race and ethnicity impact family functioning when members enter the later years.

B. **Analyze:** Identify an older person with caregiving needs. Trace the evolution of the caregiving process within the person's family. Identify the primary caregiver and his or her responsibilities as well as the roles of secondary caregiver(s). Does the older person suffer primarily from cognitive decline or functional disabilities? If cognitive deficits are the issue, how are the experiences of this individual's caregiver(s) similar to or different from those of families whose care recipient has functional problems? If functional decline is the issue, how are the experiences of this individual's caregiver(s) similar to or different from those of families whose care recipient has cognitive problems?

C. **Interview:** Choose a caregiver who has utilized adult day care or a respite program for a family member, or a caregiver support group for himself or herself. Interview the caregiver to analyze how they view the program, the extent to which they feel participation (either their own or their family member's) improves their quality of life (or that of the care recipient), what they see as the advantages/disadvantages, and so on.

Experimental/ Clinical Experiences

Attend and report on a support group meeting or visit and report on an adult day care program.

D. **Care Plan:** Develop a plan of care for a frail older adult, including the individual's primary caregiver based on the case of Ms. R. and her daughter Ms. S.

   1. Develop a decision plan for Ms. R.
   2. Are there any risks of elder mistreatment? If so, what are they?
   3. What can be done to support Ms. S.?

E. **Assessment:** With supervision, use the Elder Abuse assessment form on patients in a clinical setting.

Evaluation Strategies

1. Use any of the experiential activities as a basis for written assignments used for evaluation.
2. Create true/false or multiple choice questions based on definitions of elder mistreatment.

Topic 16: *Caregiving/Mistreatment of Older Adults*

Resources

A. Caregiving

Gatz, M., Bengtson, V. L., and Blum, M. (1990). Caregiving Families. In J. E. Birren and K. W. Schaie (Eds). *Handbook of the Psychology of Aging* (3rd ed.). New York: Academic Press.

Greenberg, S. A., Ramsey, G. C., Mitty, E. L., and Fulmer, T.T. (1999). Elder Mistreatment: Case Law and Ethical Issues in Assessment, Reporting, and Management. *Journal of Nursing Law, 6*(3), 7–20.

Horowitz, A. (1985). Family Caregiving to the Frail Elderly. In C. Eisdorfer (Ed.), *Annual Review of Gerontology and Geriatrics* (Vol. 5). New York: Springer-Verlag.

Mace, N. L., and Rabins, P. (1981). *Thirty-Six Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementia and Memory Loss in Later Life.* Baltimore: Johns Hopkins University Press.

Naylor, M., Brooten, D., Campbell, R., Jacobsend, B., Mezey, M., Pauly, M., and Schwartz, S. (1999, February). Comprehensive Discharge Planning and Home Follow-up of Hospitalized Elders: A Randomized Controlled Trial. *Journal of the American Medical Association, 281*(7), 613–620.

Robinson, K. M. (1997). Family Caregiving: Who Provides the Care, and at What Cost? *Nursing Economics, 15*(5), 243–247.

Seltzer, M. M., and Wailing, L. (1996). Transitions of Caregiving: Subjective and Objective Definitions. *Gerontologist, 36*(5), 614–626.

Semple, S. J. (1992). Conflict in Alzheimer's Caregiving Families: It's Dimensions and Consequences. *Gerontologist, 36*(5), 648–655.

Wallace, D. C., Witucki, J. M., Boland, C. S., and Tuck, I. (1998). Cultural Context of Caregiving with Elders. *Journal of Multicultural Nursing and Health, 4*(3), 42–48.

Videotapes

Hoffman, D. (1994). *Complaints of a Dutiful Daughter*, Women Make Movies, 462 Broadway, Room 500, New York, NY 10013; 212-925–0606.

Resources for Caregivers

Alzheimer's Association
800-621-0379; http://alz.org

Resources

American Association for Retired Persons
202-872-4700; www.aarp.org

Children of Aging Parents
215-945-6900; www.careguide.net

National Association of Area Agencies on Aging
202-296-8130; www.n4a.org

National Council on Aging
202-479-1200; www.ncoa.org

National Rehabilitation Information Center
800-346-2742; www.naric.com

B. Elder Mistreatment

Abuse and Neglect of Older People. (2000, Summer). *Generations, 24*(2).

American Medical Association. (1992). *Diagnostic and Treatment Guidelines on Elder Abuse and Neglect*. Chicago: American.

Beers, M., and Berkow, R. (2000). *The Merck Manual of Geriatrics* (3rd ed.). Whitehouse Station, NJ: Merck and Co.

Campbell, R. L., Naylor, M. D., and the NICHE Faculty. Discharge Planning and Home Follow-Up of Elders. In I. Abraham, M. M. Bottrell, T. Fulmer, and M. Mezey (Eds.), *Geriatric Nursing Protocols for Best Practice* (p. 189). New York: Springer Publishing Company.

Fulmer, T. (1999). Elder Mistreatment. In M. Stanley and K. Blair (Eds.), *Instructor's Guide of Stanley and Beare: Gerontological Nursing, A Health Promotion/Protection Approach* (2nd ed., pp. 157–163). Philadelphia: FA Davis Co.

Fulmer, T. (1999). Our Elderly: Harmed, Exploited, Abandoned. *Reflections, 25*(3), 16–18.

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Resources

Fulmer, T., and O'Malley, T. (1987). *Inadequate Care of the Elderly: A Health Care Perspective on Abuse and Neglect.* New York: Springer.

Fulmer, T., and Walker, M. (1992). Elder Mistreatment Assessment as a Part of Everyday Practice. *Journal of Gerontological Nursing, 18*(3), 42–45.

Humphries Lynch, S. (1997, January). Elder Abuse: What to Look For, How to Intervene. *American Journal of Nursing, 97*(1).

Luggen, A.S (1996). *Core Curriculum for Gerontological Nursing.* St. Louis, MO: Mosby.

Maddox, G. et al. (Eds.). (2001). *The Encyclopedia of Aging* (3rd ed.). New York: Springer Publishing Company.

Mezey, M. et al. (Eds.). (2001). *The Encyclopedia of Elder Care.* New York: Springer Publishing Company.

Video Resources

National Center on Elder Abuse (Producer). (1995, July). *Elder Abuse Video Resources: A Guide for Training and Public Education* (3rd ed.).

A copy of the guide is available from the National Center on Elder Abuse for $8.00, including shipping and handling. For information, call Mary Jesukiewicz of the NCEA staff at 202-682-0100 or 202-682-2470.

(This comprehensive guide to videos on elder abuse covers such topics as caregiver stress, elders as crime victims, financial exploitation, gatekeeper programs, institutional elder abuse, laws and regulations, multidisciplinary teams, minority elders, and self-neglecting elders.)

Sample Videos:

Adult Abuse
SC/ETV Marketing; Columbia, SC

Elder Abuse: Whose Problem?
Elder Abuse Project; Pittsburgh, PA
412-622-6410

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Resources

Elder Abuse: Five Case Studies
Fanlight Productions; Boston, MA

A Safer Place
Fanlight Productions; Boston, MA

Identifying & Managing Elder Abuse
Network for Continuing Medical Education; Secaucus, NJ

The Golden Years?
Fanlight Productions; Boston, MA
800-937-4113

Lifeline: Preventing Elder Abuse
Arthur Mokin Productions; Santa Rosa, CA
800-238-4868

Resources for Elder Mistreatment
National Citizen's Coalition for Nursing Home Reform (NCCNHR)
202-332-2275; www.NCCNHR.org

National Center on Elder Abuse
202-898-2586; www.gwjapan.com/NCEA

The National Association of State Units on Aging (NASUA)
202-898-2578; www.aoa.dhhs.gov/aoa/dir/137.html

Clearinghouse on Abuse and Neglect of the Elderly (CANE)
302-831-8546; www.aoa.dhhs.gov/aoa/dir/78.html

Committee for the Prevention of Elder Abuse
508-793-6166

American Association of Retired Persons (AARP)
202-434-2277; www.aarp.org

The Coalition of Advocates for the Rights of the Infirm Elderly (CARIE)
215-545-5728; www.carie.org